FORGETTING ADVANCE DIRECTIVES: DEMENTIA, AUTONOMY, AND EUTHANASIA

by
Isaac Bruce Wright

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ABSTRACT

A diagnosis of dementia is frightening for patients, as well as their family. Faced with such a diagnosis, some patients may opt for suicide, assisted death, or euthanasia. In some jurisdictions, advance euthanasia directives allow for these wishes to be fulfilled after patients lose decision-making capacity. But such directives face a unique challenge in the context of dementia, particularly because of the changes the disease inflicts on patients. On strong views of the longevity of advance directives, such changes are insufficient to challenge the authority of advance directives. Weak views, by contrast, assert that the changes wrought by dementia are often sufficient to negate the authority of advance directives. Despite their differences, both strong and weak views accept precedent autonomy as justifying a prima facie obligation to follow advance directives. This reliance on precedent autonomy, I suggest, is at the root of the challenge that advance directives face in the case of late-stage dementia.

In response to this challenge, I will propose that a cohesive understanding of advance directives without the concept of precedent autonomy is possible. On such an account, advance directives may be authoritative insofar as they are reflective of current or future

contemporary autonomous wishes. This nullifies the obligation to follow advance directives for the patient's own sake, when they lack contemporary autonomy and/or will not regain it. Despite this, incorporating the contemporary interests of the patient's family into treatment decisions may justify adherence to an advance directive when it yields a permissible outcome for the current patient. Such an account is not only plausible in theory, but faces the challenge of dementia with more permissible results than either strong or weak views of advance directives. Specifically, this account allows for both robust consideration of the contemporary experiential interests of the patient in late-stage dementia, as well as adherence to an advance directive when permissible. Abandoning precedent autonomy, I argue, more plausibly explains the role that advance directives should play in the context of euthanasia for late-stage dementia patients.

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§ 1.0 – INTRODUCTION

Dementia in its most common form, Alzheimer's Disease, affects between 5-10% of people over 65, and 50% of people over 85.[1] In its early stages, dementia may not pose a burden so severe that one would contemplate euthanasia. For most, though cognitive abilities may decline noticeably, they will remain functionally independent, and competent.[2] But in its later stages, dementia poses a more pernicious threat: the loss not only of competence, but the loss of what made the patient themselves. They may lose their ability to comprehend language, develop delusions, hallucinations, or paranoia, and become aggressive with caregivers and family.[3] Dementia, if a patient lives to its late stages, will render a patient quite unlike they were before – unable to make competent decisions, or provide insight into their own care needs. This drastic change generates our problem: how do we view the wishes of someone who is so different from how they once were? Further, how do we evaluate what is good for this changed patient considering the irreversibility of euthanasia or assisted death?

Faced with a diagnosis of dementia, a patient may explore the idea of ending their life before the disease takes its toll. The question of assisted death for dementia patients is not hypothetical. Some form of assisted dying is legal in the Netherlands, Belgium, Luxemburg, Switzerland, Germany, Canada, and ten American states. The exact nature

[1] Zoe Arvanitakis, Raj C. Shah, and David A. Bennett, "Diagnosis and Management of Dementia: Review," *JAMA* 322, no. 16 (October 22, 2019): 1589, https://doi.org/10.1001/jama.2019.4782.
[2] Marilyn S Albert et al., "The Diagnosis of Mild Cognitive Impairement Due to Alzheimer's Disease: Reccomendations from the National Institute on Aging-Alzheimer's Association Workgroups on Diagnostic Guidelines for Alzheimer's Disease," *Alzheimer's & Dementia* 7 (2011): 270–79, https://doi.org/10.1016/j.jalz.2011.03.008.
[3] Arvanitakis, Shah, and Bennett, "Diagnosis and Management of Dementia."

of such systems varies. Most offer only assisted suicide, where the patient may self-administer a lethal drug, or consume it with the aid of a physician (or other licensed healthcare professional). In some jurisdictions, though patient assistance in the procedure is unnecessary, consent is required up until the point of administration. As a result, almost all jurisdictions which do allow for assisted death require the patient be competent at the time of their death. This is a limiting factor for some terminally ill patients, who fear they will be incapacitated before they are able to consent to their assisted death. Of these countries only the Netherlands currently allows for an advance euthanasia directive (AED)[4], which allows a patient to stipulate when and how they would like to receive euthanasia after they are deemed decisionaly incompetent. In 2017, the most recent year for which we have complete data, 169 people with dementia were euthanized in accordance with their AED in the Netherlands.[5] In three of these cases, dementia had advanced to the point that the patients could no longer communicate, raising objections that the patients could no longer consent to their death, and may not share their past wishes.[6]

In Canada, the government has moved to approve a bill[7] to allow for a waiver of final consent, which would allow a patient to specify that euthanasia be carried out on a specific future date, regardless of the patient's capacity. This waiver of final consent is

[4] *Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding [Termination of Life on Request and Assisted Suicide (Review Procedures) Act],* 1 April 2001, *Stb.* 2001,137.
[5] Regional Euthanasia Review Committees, "Annual Report 2017" (The Hague, Netherlands: Government of the Netherlands, April 2018), https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports.
[6] Regional Euthanasia Review Committees.
[7] Bill C-7, *An Act to amend the Criminal Code (medical assistance in dying),* 1st Reading Feb 24, 2020, 1st sess., 43rd parl., 2020. https://www.parl.ca/DocumentViewer/en/43-1/bill/C-7/first-reading

an advance euthanasia directive by another name. Such a waiver is of particular interest to those with neurodegenerative diseases, who fear waiting too long and thus losing capacity, or who fear having an assisted death earlier, forgoing some amount of life that they would believe is acceptable. Despite the challenges posed by the current legislation, patients with neurodegenerative diseases make up over 10% of total assisted deaths in Canada annually.[8] Those who care for people suffering with dementia in Canada have demonstrated willingness to implement. In Quebec – the second largest province, with nearly a quarter of the Canadian population – euthanasia by AED for those with late-stage dementia is supported by 45% of physicians,[9] 83% of nurses,[10] and 83% of informal caregivers.[11] This support increased to 71% of physicians[12] and 91% of caregivers[13] when the patient was classified as being in the terminal stages of their illness. Combining this wide openness to euthanasia directives for dementia patients, with the legal leeway to perform euthanasia for such patients, it seems likely that Canada will soon face the same ethical questions which currently face the Dutch. Of further note in the Canadian context Is the sheer speed of change to assisted death policy. Bill C-7, allowing for advance euthanasia directives, was tabled a

[8] Health Canada, *Fourth Interim Report on Medical Assistance in Dying in Canada.*, 2019, http://publications.gc.ca/collections/collection_2019/sc-hc/H14-230-4-2019-eng.pdf.
[9] Gina Bravo et al., "Quebec Physicians' Perspectives on Medical Aid in Dying for Incompetent Patients with Dementia," *Canadian Journal of Public Health* 109, no. 5–6 (December 2018): 729–39, https://doi.org/10.17269/s41997-018-0115-9.
[10] Gina Bravo et al., "Nurses' Perspectives on Whether Medical Aid in Dying Should Be Accessible to Incompetent Patients with Dementia: Findings from a Survey Conducted in Quebec, Canada," *Geriatric Nursing* 39, no. 4 (July 2018): 393–99, https://doi.org/10.1016/j.gerinurse.2017.12.002.
[11] Gina Bravo et al., "Are Informal Caregivers of Persons With Dementia Open to Extending Medical Aid in Dying to Incompetent Patients? Findings From a Survey Conducted in Quebec, Canada:," *Alzheimer Disease & Associated Disorders* 32, no. 3 (2018): 247–54, https://doi.org/10.1097/WAD.0000000000000238.
[12] Bravo et al., "Quebec Physicians' Perspectives on Medical Aid in Dying for Incompetent Patients with Dementia."
[13] Bravo et al., "Are Informal Caregivers of Persons With Dementia Open to Extending Medical Aid in Dying to Incompetent Patients?"

mere five years after the 2015 legalization of assisted death in *Carter v. Canada.*[14] The pace of this change makes questions of euthanasia and advance directives even more relevant, even for jurisdictions who believe they are years away from legalization.

Those facing dementia, then, may think seriously about taking control of their own deaths. In Canada and the Netherlands, this is no hypothetical – they can, and do pursue euthanasia or assisted suicide to avoid a fate they find intolerable. In some jurisdictions, euthanasia may be requested via advance directives by dementia patients. In other jurisdictions, this may not be possible for some time, if at all. The minutia of public opinion on euthanasia, certainly a research project in its own right, is not my focus here. Suffice it to say that jurisdictions have shown a track record of gradual liberalization of assisted death laws, as has Canada, from assisted suicide to AED. It is possible that other jurisdictions will have similar evolutions. If nothing else, the very existence of such liberalized euthanasia regimes serves as a prompt for argument about their morality. This paper is focused, considering the situation at hand, on a narrow, essential question: How should we view, in moral terms, the authority of an AED when the patient will face late-stage dementia?

I will argue that dementia poses such a threat to our understanding of advance directives, and autonomy, that we have ought to consider an account of advance directives which rejects precedent autonomy. Advance directives, on this view, serve to

[14] *Carter v. Canada (Attorney General)*, [2015] 1 S.C.R. 331

mark the boundaries of what a patient considers acceptable treatment considering their preferences and values. The moral weight of advance directives comes from their utility in avoiding a future in which a patient is forced to live in a state where their critical interests are actively thwarted, and their autonomy limited. Dementia makes such a future impossible for a large swathe of patients, thereby weakening the strength of advance directives.

Recognizing that dementia reduces our obligation to follow advance directives for the patient's sake does not restrict our ability to do so for other reasons. Nor does it entail that we simply defer to a contemporary best interests standard. In fact, embracing my revised view allows us to integrate, and better conceive of, the interests of the loved ones of a patient. Such interests carry weight, and may be decisive in care decisions where there are multiple courses of action which all have permissible clinical outcomes. In such cases, families have a clear prerogative to influence care in one way or another. Further, if their wishes coincide with the patient's now nullified advance directive, this opportunity can provide some degree of solace to families and loved ones, in seeing the patient treated in a manner which would have suited their former self. Such an outcome can be provided, even on an account where directives are radically weakened.

§ 2.0 – THE ARGUMENT THUS FAR

The discourse on advance directives and dementia has a wide spectrum of participants: the 'strong' defense of advance directives headed by Dworkin, the 'psychological

continuity' rebuttal of the 'strong' defense championed largely by Rebecca Dresser, and other prominent theorists, such as Jeff McMahan, falling more or less in the middle. Though Dworkin's view is most aptly described as the orthodox view, all accounts explored in §2 accept the premise that advance directives have lasting weight for patients who are permanently incapacitated. They disagree on the ease with which such directives may be overridden, by contemporary experiential interests, or rendered moot by a lack of interests in continued life. I will argue that this premise warrants reconsideration – that we should explore an alternative account which disregards precedent autonomy altogether.

§ 2.1 – Strong views

Dworkin argues for a strong view of the longevity of advance directives on which violating advance directives is a serious violation of respect for one's autonomy. Advance directives are representative of 'critical interests': the broader picture of what one wants their life to mean, and the coherent system of values by which one lives.[15] Dworkin contrasts critical interests with experiential interests: the things we like to do, the pain we feel is tolerable, etc.[16] The former interests have priority over the latter, since frustrating critical interests affects the meaning of one's entire life, whereas frustrating experiential interests frustrates only one's contemporary desires for something comparatively mundane. Formalizing critical interests, in the form of an advance directive, protects one from having them violated should one lose capacity to

[15] Ronald Dworkin, *Life's Dominion* (New York: Vintage, 1992), 200.
[16] Dworkin, 200.

voice them oneself. In cases of late-stage dementia, Dworkin is clear that critical interests should have priority over potentially conflicting experiential interests. An advance directive may only be crafted by a patient with capacity – the requisite autonomy to reflect on their critical interests and the cohesive shape of their life.[17] These considered wishes may only be overruled by a patient who later engages in a considered judgement, revising their critical interests. Since dementia patients (insofar as they lack capacity) are unable to do this, we must abide by their advance directives. Failing to do so, on Dworkin's view, would disrespect the broader value of their life, even if we intended to respect their contemporary interests.[18]

McMahan endorses an embodied mind account of personal identity, on which even if a later dementia patient lacks the sort of meaningful psychological connection to their prior self, they are still the same individual, validly subject to their advance directives.[19] Contrary to Dresser and Parfit, a lack of psychological continuity caused by late stage dementia does not make the demented patient a *different* person. It instead makes the demented patient a non-person, or potentially a changed person, though still the same individual by virtue of their having maintained the same embodied mind.[20] Such change would warrant a discounting of the power of advance directives, but not complete disregard for them. McMahan maintains that advance directives may still be authoritative particularly in end-of-life decisions for demented patients. Considering the

[17] Dworkin, 206.
[18] Ibid, 231.
[19] Jeff McMahan, *The Ethics of Killing: Problems at the Margins of Life* (Oxford: Oxford University Press, 2002), 494.
[20] McMahan, 495.

interests expressed by the advance directive, and the comparatively weak interests in a demented patient in continued life (considering their lack of forethought, quality of life, etc.) these prior interests can outweigh their interests in continued life, even if they no longer share or comprehend of their past directive.[21]

Accounts on Dworkin's side of the spectrum face problems insofar as they undervalue contemporary interests and overvalue precedent autonomy, producing outcomes of which we should be suspect. The root of this suspicion, I assert, is reliance on precedent autonomy. Dworkin considers a scenario in which a dementia patient crafts an AED which stipulates she be killed[22] in the late stages of her dementia.[23] Let us call this *Case **A***. On both the grounds of her precedent autonomy, and that of beneficence (particularly towards her critical interests) we should abide by such a directive, even in the face of conflicting interests (i.e., vocalized desire to live).[24] In respecting the patient as a whole person, rather than just as her later demented self, we are obligated on this view to abide by her critical interests and execute the advanced euthanasia directive. McMahan would presumably come to a similar conclusion, though on the grounds that

[21] McMahan, 502.
[22] In this section of his considerations, Dworkin treats the case as requesting comfort care only, though he mentions that "They may consider trying to make the other arrangements I mentioned: to have their money given away, or even, if possible, to be killed (…) Is there a conflict between respecting Margo's precedent autonomy, if she had signed such a living will, and doing what would later be in her best interests?" (230) Though he treats the case as if she requested that life sustaining care be forgone, I will address his more severe hypothetical, that she requests euthanasia. I do this in part because he mentions it in the same breath as other life-ending or life-shortening requests, and also because if his account should stand scrutiny, it should apply successfully to euthanasia as well.
[23] Dworkin, *Life's Dominion*, 227.
[24] Ibid, 231.

her time-relative interest in continuing to live are outweighed by her broader interests in dying in a manner which comports with her life's values.

Both of the above conclusions are plausible, and we should accept them. But consider what the treatment of a patient in a reverse of the above case would entail:

> **Case B**: A patient, B, crafts an advance directive that demands maximal therapy even into the deepest throws of late-stage dementia. Years later, her outlook changes dramatically: profoundly demented, she forgets her name, her family, her whereabouts, and lacks a basic understanding of her situation. B requests, frequently, and verbally, that nurses "let her die" and resists all efforts at hand feeding.

We should not condone aggressive measures at this point. A feeding tube, for such a patient, could entail limb restraints to prevent resistance: causing a great deal of distress for someone with no understanding of their purpose.[25] Further, should B contract an illness like COVID19,[26] the potential life-sustaining measures include catheterization, ventilation, and chest compressions: measures which would incur lasting damage and pain even if successful. The measures requested are too drastic, the benefits too few. Dworkin's account cannot withstand the challenge of case ***B,*** since the strength he gives advance directives would entail that, as expressions of their

[25] Further, using a feeding tube at this point in dementia would be against clinical guidelines. See: American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee, "American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement," *Journal of the American Geriatrics Society* 62, no. 8 (August 2014): 1590–93, https://doi.org/10.1111/jgs.12924.
[26] For a recent account of the difficulties of a lack of advance directives for end-of-life decisions in the wake of COVID-19, see: Joel Rowe, "The Pandemic Should Change the Way We Talk About Dying," *The Atlantic*, July 3, 2020, https://www.theatlantic.com/ideas/archive/2020/07/pandemic-should-change-way-we-talk-about-dying/613618/.

autonomy and reflective of their critical interests, we implement these drastic and cruel treatments.

In case ***A***, of which McMahan uses a facsimile in his work,[27] the weak interest in continued life makes it easily overruled by an advance directive favoring death. One could draw a distinction based on the interest in avoiding pain in this case: though B has a negligible interest in continued life (supporting the advance directive), she has a stronger interest in avoiding the pain of gastrostomy or resuscitation, which outweighs the advance directive. But this claim would be inconsistent with the rest of McMahan's view. In ***A,*** McMahan asserts that the time-relative interest in life is sufficiently weak to be overruled by the patient's interest in dying.[28] McMahan must accept that the time-relative interest in avoiding pain is similarly weak in ***B,*** allowing the advance directive to be abided by. If this is true, his account allows for a directive to require irresponsible medical treatment. We should find that this ignorance of later, comparatively 'weak' interests in ***B*** condemns McMahan's view, even if it does not strike us as wrong in ***A.***

Both Dworkin and McMahan may make concessions to their initial theories. Dworkin may assert that our discomfort in case ***B*** is reflective of other reasons which validly override our reason to abide by B's advance directive, not reflective of a weakness of the advance directive itself or of precedent autonomy. McMahan may assert that a distinction is drawn between avoiding pain and continuing to live which makes a weak

[27] McMahan, *Ethics of Killing,* 497.
[28] Ibid, 451.

time-relative interest in the former stronger than one in the latter. What these concessions show, however, is that the patient's contemporary best interest, not their advance directive, is what legitimizes the goal in these cases. In ***A***, it is plausible that the hastened death of the patient is permissible, but not obligatory: therefore, an advance directive which hastens death seems similarly permissible. In ***B***, by contrast, it is plausible that subjecting the patient to such pain would be impermissible: therefore, an advance directive which would inflict such pain is unjustified. Judgement in these cases is responsive not to the moral weight of an advance directive, but rather to our judgements about what would be a good outcome for the patient in their current state.

§ 2.2 – Weak views

On the psychological continuity view, prompted broadly by Parfit[29] and championed specifically by Dresser, the strong view is flawed because the later dementia patient is no longer meaningfully the same person who crafted the advance directive. This account does not necessarily hold that the later demented patient, in having interests contrary to their past directive, is a *numerically* different individual than the patient at onset. It instead holds that the later demented patient may have changing preferences which should be respected in order to prevent making a patient subject to preferences they no longer share.[30] In saying the patient is no longer relevantly themselves, those working in this vein may hold either that the patient is actually a distinct individual, a

[29] Derek Parfit, *Reasons and Persons* (Oxford: Oxford University Press, 1984), for Parfit's general view of the psychological account of personal identity, and see p 327 specifically for his view of later negation of precedent autonomy, in *the 19th Century Russian*.
[30] Rebecca Dresser, "Treatment Decisions and Changing Selves," *Journal of Medical Ethics* 41, no. 12 (December 2015): 975–76, https://doi.org/10.1136/medethics-2014-102237.

non-individual, or that they are the same individual but with radically shifting preferences, values[31] or experiences. [32] Rather than attempt to comport with past directives, Dresser and others have maintained that clinicians should abide more (or exclusively) by the patient's current interests. Further, they question the wisdom of advance directives altogether, questioning the degree to which anyone may make judgements about their later subjective state in late-stage dementia.[33] This approach has obvious difficulties, not least of which involve the ability of clinicians to obtain reliable information about the subjective experience of those in late stage dementia, and determining what constitutes a 'life worth living' for someone without consulting their advance directive as authoritative.[34]

Views on Dresser's side of the spectrum seem to take my earlier critique to heart. What they are concerned with fundamentally are contemporary, interests of the patient when these interests conflict with past ones. But they too face challenges, since they accept a crucial first premise of the strong view of advance directives. This is the premise that advance directives gain their moral strength from the precedent autonomy of the patient. What makes them weak accounts of advance directive longevity is the fact that

[31] For an account on which advance directives may ignore the ability of a late-stage dementia patient to value, see Agnieszka Jaworska, "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value," *Philosophy & Public Affairs* 28, no. 2 (April 1999): 105–38, https://doi.org/10.1111/j.1088-4963.1999.00105.x.
[32] For a recent account on which advance directives are undermined by transformative experience, see Emily Walsh, "Cognitive Transformation, Dementia, and the Moral Weight of Advance Directives," *American Journal of Bioethics* Forthcoming (2020).
[33] Rebecca Dresser, "Dworkin on Dementia: Elegant Theory, Questionable Policy," *The Hastings Center Report* 25, no. 6 (November 1995): 32, https://doi.org/10.2307/3527839.
[34] Rebecca Dresser and John A. Robertson, "Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach," *Law, Medicine and Health Care* 17, no. 3 (September 1989): 234–44, https://doi.org/10.1111/j.1748-720X.1989.tb01101.x.

they believe such interests are null and void pending psychological disunity, cognitive change, or due to a lack of predictive ability. But at times, they make a strong claim in the opposite direction. Dresser has articulated this on multiple occasions, arguing that those diagnosed with early dementia need more information on what the experience of dementia would be like before taking decisive action or making a directive,[35] and comparing dementia to other clinical situations where our predictions about how happy we are with a disease or an injury are inaccurate compared to patient outcomes.[36] On this account, it would seem misguided to craft directives while ignoring the possibility of erroneous predictions, or the possibility of a lack of knowledge about the experience of dementia.

Jaworska goes further than suggesting that mere preferences can change over the course of dementia. She asserts that the ability to value is maintained through dementia, though the disease may preclude any patient from acting on such values.[37] This entails not only that we should treat dementia patients as subjects who value, but also as subjects who can have a change in what they value, as their disease progresses. Walsh argues that because dementia is essentially a "transformative experience," the rational thing to do upon receiving a dementia diagnosis is to let yourself experience these preference changes as the disease goes on.[38] This

[35] Rebecca Dresser, "A Fate Worse Than Death?: How Biomarkers for Alzheimer's Disease Could Affect End-of-Life Choices," *Indiana Health Law Review* 12, no. 2 (October 27, 2015): 651, https://doi.org/10.18060/3911.0004.
[36] Dresser, "Treatment Decisions and Changing Selves."
[37] Jaworska, "Respecting the Margins of Agency," 131.
[38] Walsh, "Cognitive Transformation, Dementia, and the Moral Weight of Advance Directives," 21.

conclusion shows her broader claim that an advance directive, for dementia patients, thwarts what may be valid changes in preferences from being attended to by caregivers.

On any of the weak accounts, an objective best interests standard would dictate the clinical course of action once a dementia patient was sufficiently different from their past self to undermine their advance directive. But such a best interests standard is less than conclusive, and may provide vague direction. There are often several courses of action exist which may be permissible, or reasonably be conceived as keeping the patient's best interests in mind. Faced with a dementia patient with minimal understanding of their situation, little interest in life, but little pain or distress, several outcomes are permissible. Their quick and painless natural death, their continued life, succumbing to a respiratory infection, palliative sedation, are all permissible outcomes. Reverting simply to a best interests standard leaves us directionless in these cases. It would be inconsistent, on the weak views, to default to the past advance directive. Since (echoing the strong view) advance directives represent narrative interests, and this later person is no longer relevantly the same person as the person who crafted such an advance directive, it is illegitimate to apply such a directive even in the absence of a conflicting contemporary interest.

§ 3.0 – RECONSIDERING ADVANCE DIRECTIVES

My discussion thus far has been insufficient to prove conclusively that the orthodox conceptions are illegitimate, or unsalvageable. But I believe I have shown that dementia

poses a challenge to our current understanding of advance directives and autonomy. Adherence to a strong account of longevity runs the risk of legitimizing pointless or even harmful treatment which the patient can no longer value in the way they once did. The weak account, however, lacks clear guidance, and insofar as it is patient-centered it ignores what seem to be valid interests of loved ones, even when accommodating them may yield permissible outcomes. This challenge warrants attention, either in considerations of how existing accounts may accommodate such concerns, or in a broader reconsideration of our theories. I will take the latter approach.

Revisiting the foundations on which Dworkin builds his understanding of precedent autonomy and advance directives, I will outline a minimalist account of advance directives which departs from both the strong and weak view of the longevity of advance directives. We can maintain, I argue, a plausible account of the power of advance directives which comports with permissible clinical outcomes, without relying on precedent autonomy. Moreover, ignoring precedent autonomy as generating obligations to follow advance directives allows us to accommodate cases of late-stage dementia without engaging with the more difficult question of identity.

In refreshing our assessment of the nature of advance directives, consider Dworkin's Jehovah's Witness case, which he uses to justify his broader intuitions about advance directives and precedent autonomy:

> ***JW:*** A Jehovah's Witness patient signs a directive which states that should he require a blood transfusion to save his life, he be denied one (because of his

> religious beliefs) even if he later countermands his directive and pleads for a transfusion. He later requires a transfusion, and begs for it to be administered.[39]

Dworkin's assessment of this case is that we would not be violating his autonomy by administering the transfusion if the patient were competent when he made his later demand. But if we were confident that the patient was incompetent when he made his later demand (the effects of medication, pain, or temporary brain injury), we have, on Dworkin's view, an obligation not to administer the transfusion. Administering the transfusion in this case would mean the patient "would become competent again and become appalled at having had a treatment he believed worse for him than dying."[40] That we would not administer the transfusion in this latter case is evidence that we believe precedent autonomy is genuine. We should abide by it, on his view, not because we really think that the patient still shares these wishes. Rather, the directive is authoritative since countermanding a past autonomous decision is impermissible, unless the patient autonomously negates it.[41]

Dworkin rejects the view that it is the prediction that the patient will regain consciousness which does the moral heavy lifting. Such a view would see precedent autonomy as unnecessary for the execution of the above directive. He argues that this prediction would be similarly true if the Witness's plea for a transfusion was fully autonomous – we could very well guess that he would later regret this, as his actions conflict with the values he holds, and those of his community. Yet we would have to, in

[39] Dworkin, *Life's Dominion*, 227.
[40] Ibid.
[41] Ibid.

this case, abide by his later wishes not because we thought he would never come to regret it, but because it was an autonomous demand.[42] Therefore the value we place on advance directives are demanded by autonomy, rather than beneficence. While I agree with Dworkin that in the latter case we would be obligated to provide the transfusion, I disagree that this conclusion provides, as he asserts, a sweeping justification for precedent autonomy and advance directives.

Just because we accept the supremacy of contemporary autonomy when the patient makes an autonomous later request does not automatically entail that we ignore their incompetent request to protect precedent autonomy. Dworkin is correct that contemporary autonomy motivates us to provide the patient with the transfusion should they make a competent request which conflicts with their earlier preference. In this case, respect for autonomy gives us ample reason to comply. But when the patient makes an incompetent request, we may continue adhering to their advance directive insofar as it is an indication of the critical interests they would come to experience should they regain competence. We might act, when the patient's latter request is incompetent, out of concern to avoid a state of affairs which they would find detestable, and in the absence of indication that this is no longer the case. The extent to which the patient would find their future detestable is largely determined by their contemporary autonomy, and the critical interests they hold. Precedent autonomy is not necessary for such an understanding.

[42] Dworkin, 228.

When a patient has contemporary autonomy, their request usurps their past directive even if we believe they will come to regret this. When they are making their later demand incompetently, however, we may continue to avoid the blood transfusion on grounds other than precedent autonomy. We are faced with two outcomes: we allow the patient to die, or we subject the patient to a life during which their contemporary autonomy, and critical interests, are actively limited and suppressed.[43] Considering those two outcomes, the former option is preferable, because it allows the patient to avoid something they view as worse than death. Advance directives have force, then, insofar as they aid us in avoiding outcomes which would subject the patient to a state in which their autonomy is overridden against their will. The suggestion that precedent autonomy is unnecessary in legitimizing our adherence to advance directives does not mean we should similarly weaken our respect for contemporary autonomy. Rather it is contemporary autonomy which is of concern in both cases of competent and incompetent requests. When competent, we respect contemporary autonomy by following their request – even if we believe it is misguided. When incompetent, we can respect the patient's future contemporary autonomy by ignoring their request. Precedent autonomy needs not have anything to do with our deliberations in such a case – that is not what makes advance directives reason-giving. Instead, we may view an advance directive as reason-giving insofar as it serves as evidence of current or future contemporary autonomous wishes and/or critical interests.

[43] This holds only if we have a reasonable degree of certainty that the patient would be in a state to share their prior religious convictions. If there was reason to believe that they may awake in a cognitively altered state, we should radically devalue their directive, as I will later argue.

I argued in *§2* that the case of dementia poses a challenge to advance directives – a challenge which warrants broad reconsideration of precedent autonomy as generating obligations to follow advance directives. Though contemporary autonomy provides reason to reject a past directive even when we believe it has bad outcomes, such an assumption does not entail that when a patient is incapacitated we are acting in the interest of protecting the patient's precedent autonomy. What Dworkin views as essential to advance directives, I suggest, is unnecessary.

We can maintain an appreciation of contemporary autonomy without immediately assuming such autonomy is lasting. When a patient has contemporary autonomy, their competent decisions have supremacy, and we should act on them. But once a patient is unable to conceive of the very critical interests their autonomous directive was meant to protect, we lack an obligation to abide by such directives. When a patient lacks contemporary autonomy, we should act to avoid subjecting them to some future state of affairs in which their contemporary autonomy and critical interests are knowingly thwarted. In this light, an advance directive should be adhered to insofar as it provides an indication of what they will find a tolerable state when they regain competence. Moreover, it protects their contemporary autonomy and critical interests in the future, once they recover.

There are patients for whom later appreciation of their critical interests is impossible. Such patients may be suffering from late-stage dementia – the primary focus of this

paper – be in a permanent vegetative state, brain dead, or have sustained a severe brain injury producing permanent cognitive impairment, etc.[44] These patients lack both contemporary autonomy (allowing them to affirm or negate their directive in or against their critical interests) and the prospect of regaining the ability to conceive of their critical interests in the future. For these patients, the force of their past advance directive is completely negated by the certainty that they will not come to realize their critical interests have been thwarted – their past autonomy disregarded.

Though we have no reason to adhere to advance directives for such patients' own sake, we may have reason to adhere to advance directives on other grounds. Advance directives fail to generate obligations to act in a certain way on the patient's behalf once they cease the ability to experience their critical interests. But violations of these former interests will affect those who care about them: spouses,[45] family, and caretakers,[46] for instance. These critical interests play a foundational role in the way that family members and friends may deal with the loss of a loved one, especially when that loved one, though still breathing, barely resembles the person they used to know. Such is the case in late stage dementia. The family of a demented patient may be more apt to treat them

[44] It is worth noting here that this account of advance directives is subject to constraints around predictive power. Questions of conclusiveness around how severely cognitive function has been changed, how little a chance a patient has at regaining past cognitive function, coming out of a coma, etc., are challenging to answer on any view, including my own. Additionally problematic is the level of risk we may accept in such cases – the threshold of risk that a patient may re-conceive of their critical interests – before we negate an advance directive. Though such discussions are difficult, they are not unique to my view, and should not exclude it from consideration.

[45] Suzannah Clark, Tim Prescott, and Gemma Murphy, "The Lived Experiences of Dementia in Married Couple Relationships," *Dementia* 18, no. 5 (July 2019): 1727–39, https://doi.org/10.1177/1471301217722034.

[46] Kristie Kannaley et al., "Thematic Analysis of Blog Narratives Written by People with Alzheimer's Disease and Other Dementias and Care Partners," *Dementia* 18, no. 7–8 (November 2019): 3071–90, https://doi.org/10.1177/1471301218768162.

as if they were their former self, especially when treating them as their former self yields positive outcomes. Doing so may not bring comfort per se, as dementia will take an irreversible toll on the patient. But it may be preferable for the loved ones of the patient to maintain the patient's critical interests, than accept that the person they once knew now occupies a permanently truncated body and mind.

An argument to take the interests of loved ones into consideration is nothing new. But on my view, they gain increasing importance when we lack an obligation to follow a patient's former advance directive for the patient's own sake – that is, when we abandon precedent autonomy. Once a patient's advance directive has been rendered meaningless by their dementia, we may default to whatever would yield a permissible clinical outcome. We may default, for example, to a contemporary patient interests standard.[47] But in some cases, particularly for terminal illnesses and decisions at the end of life, many courses of action may be permissible. Unlike Dresser's view, on my view an advance directive is not useless once its meaning to the patient is rendered moot. Indeed we can, and should, weigh the benefits of following an advance directive for the family's sake against the burden it may cause the patient to experience.

Incorporating the desires of loved ones into the treatment of a now-incapacitated patient may preserve some of their past critical interests, and provide some solace to those who care for them. But such integration has limits, particularly when it comes down to

[47] Dresser and Robertson, "Quality of Life and Non-Treatment Decisions," 240.

the burdens one's family could impose on a later demented patient in the interest of preserving their critical interests. Dworkin's account, as I argued in *§ 2.1*, does a poor job of considering the contemporary interests of a dementia patient, precisely because it weighs precedent autonomy so highly compared to contemporary interests. On my account, there are no matters of autonomy at play once the patient has become permanently incapacitated. There are only the contemporary interests of which the dementia patient is capable, and the interests of their loved ones in seeing the patient be treated in a certain manner. The latter of these interests may serve to maintain the past advance directive, to paint a façade of continued autonomy.

It is worth noting the remoter effects that such a shift in our understanding of advance directives may have. Most pointedly, such a view would impact patients who are now, or will soon, deliberate making such a directive. Such patents, presumably, care that their advance directive will be followed, and that it should not be thrown out for no reason whatsoever. They may care about this even though they realize that their future self may not share these views, as a result of their illness. For these patients, at the time of crafting their directive, it would be comforting to know that their advance directive will not be thrown out for no reason. Though, on my view, the authority of advance directives would be more sensitive to the contemporary interests of the patient than the strong view, directives are more likely to be followed than on the weak view. This outcome is consistent with a current patient crafting an advance directive, who may take solace in the following of their advance directive, while also caring about the experience

of the later, demented patient, thus having an interest in such a directive being sensitive to contemporary interests.

There is one aspect of my account which to those who follow this debate is conspicuously absent: the challenge personal identity poses to the authority of advance directives. On the orthodox view, personal identity is important insofar as it determines who may be subject to advance directives. If our advance directives are, as such views argue, articulations of precedent autonomy, detached from our capacity to appreciate our autonomous wishes, then anyone who shares that identity is bound by their advance directive. Those who argue for the existence of pre- and post-persons, divided from the 'person' by a lack of psychological continuity and/or connection, leave open the possibility that a patient in late stage dementia is a different individual than they were before. Such a patient could not validly be subject to the advance directive of someone else. Contrary to this conclusion, McMahan argues that while it is possible that dementia renders someone a non-person, it does not result in a new numerical identity, but rather a version of their past self who fails to meet the threshold for personhood.[48]

A minimalist account of advance directives avoids complicating the identity discussion further. The continuation of identity is neither necessary nor sufficient to make one subject to their past desires or directives. Identity need not matter in advance directives. All that matters is the ability of a patient to conceive of their critical interests, and be

[48] McMahan, *Ethics of Killing*.

affected by a state in which they are deprived of those interests; further, deprived of the ability to act autonomously. Even if it were the case that a dementia patient in late stages was no longer the same individual they were at diagnosis, the family and friends of the patient at onset still retain their own interests in treatment decisions. Treatment which fails to comport with the patient as they knew them may have deleterious effects on their well-being, their ability to deal with grief after the patient's death, and the impact that the manner of death itself has on such close relations. The patient themselves, at such a point where they have lost identity, is unlikely to have distinct contemporary interests which could compete with such interests on behalf of friends and family. Even if, as some would argue, the demented patient is a different person, this does not preclude the family from maintaining the critical interests of the past patients, so long as they operate within the bounds of what we may consider a permissible outcome for the patient as they exist today. Answering the identity question is inconsequential, then, in late-stage dementia.

§ 4.0 – ADVANCE EUTHANASIA DIRECTIVES & DEMENTIA PATIENTS

To this point, I have questioned both 'strong' and 'weak' accounts of the longevity of advance directives in the face of dementia. In §2.0, I argued that, considering their counterintuitive clinical results, we should consider abandoning precedent autonomy. In §3.0, I explored the possibility that the foundations of advance directives as previously conceived may be more fragile than we believed. Both strong and weak views accept the broad premise that the values enshrined in an advance directive has some lasting objective significance, even if the patient no longer conceives of it. They disagree on the

ease with which these directives may be overruled but agree that there is something to be overruled in the first place – precedent autonomy. I reject this premise, holding that advance directives have moral force only insofar as they enable us to avoid sentencing a patient to experience a state of affairs against their critical interests. Without such a possibility, such as in the case of late-stage dementia, there is no reason to abide by an advance directive for the patient's own sake. Despite this, we may factor in the interests of family members and friends in protecting the patient's past critical interests for their own peace of mind, when the result of such preferences could still be considered as being in the patient's best experiential interests.

It is not the case that people merely 'might' want to craft an advance euthanasia directive in the face of dementia: people have done so, and by all estimations will continue to do so until a cure for dementia is found. Those who are diagnosed with dementia may pursue euthanasia for a multitude of reasons. Further, they have reasons for seeking this procedure via an advance directive or preferring to die while they still understand their situation, surroundings and loved ones, in the earlier stages of their disease. Though there are various motivations for ending one's life,[49] or hastening death, in the face of a dementia diagnosis, two broad motivations emerge both in literature and in legal considerations.

[49] For the most thorough account of motivations towards suicide in the context of dementia, see Dena S Davis, "Alzheimer Disease and Pre-Emptive Suicide," *Journal of Medical Ethics* 40, no. 8 (August 2014): 543–49, https://doi.org/10.1136/medethics-2012-101022.

The first is an interest in avoiding the process of losing one's memory, one's relationships with others, etc. Motivated by this concern, one may seek to commit suicide or seek an assisted death while one could still conceive of their critical interests being thwarted. This course of action is recognized in the assisted death legislation of both the Netherlands and Canada. But this motivation would be extremely weak in justifying euthanasia by advance directive, particularly because of the nature of dementia. The suffering of losing one's memory, relationships, and ability to function, would put at risk one's capability to comport with their critical interests. Our obligation to comply with an advance euthanasia directive on such grounds would be comparatively weak as dementia progresses. The further they progress in the stages of dementia, the less they are able to comport with their prior critical interests. Moreover, as they progress towards late stage dementia, the relationships and memories they previously sought to prevent will have been compromised. The situation they sought to avoid by euthanasia no longer being a possibility, we would have no obligation to carry it out.

The second broad motivation for suicide or euthanasia in the face of dementia is an interest in avoiding a state at the end of dementia which the patient at onset deems unacceptable. This may refer to the manner of death itself, or the existence of the terminal dementia patient as they near death.[50] This motivation falls prey to the progression of dementia in the same manner as the first. By the time the fears of those diagnosed are at the door, they will have lost the ability to conceive of their critical

[50] For one prominent example of such a view, see Norman L Cantor, "On Avoiding Deep Dementia," *Hastings Center Report* 48, no. 4 (2018): 26.

interests, thus negating our obligation to adhere to their advance directive. Both motivations, on my view, provide strong reason to end one's own life while the patient has a conception of critical interests to protect. But they provide weak justifications for advance directives, and we could not execute on them for the patient's own sake, since we would not be avoiding a situation where they would experience their critical interests as being thwarted.

Neither common motivation for suicide nor euthanasia, on my view, are sufficient to justify following an advance directive for the patient's own sake. Despite this, there are times at which it may be permissible to execute on an advance euthanasia directive for other reasons. As I argued earlier, the desire to preserve a loved one's former critical interests provide legitimate grounds on which family members, friends, and others with relationships to the patient, may seek to adhere to an advance directive in order to maintain their own sense of who the patient is, and how they should be treated. In what follows, I will outline how a minimalist account of the longevity of advance directives, one which disregards precedent autonomy, would handle various hypothetical cases in which an advance euthanasia directive exists for an incapacitated dementia patient.

The first case with which we should be concerned is a case on which family desires conflict with an advance directive:

> **Case C**: C, an 83-year-old patient with late-stage Alzheimer's Disease Dementia, crafted an advance euthanasia directive at the age of 76 which specified she be euthanized the day after her 84th birthday. Doctors expected, correctly, that by this point she would have global aphasia, fail to recognize her family members,

> her own name, and her surroundings. One week before her 84th birthday, C meets her own directive's stipulations for euthanasia. Despite her truncated abilities, C seems content with her daily life. She partakes eagerly in group exercise, laughs and smiles while watching birds in the courtyard. C eats sufficiently, has no underlying health issues, and is in no discernible pain. Workers in her facility describe C as their 'happiest resident.'
>
> When presented with these facts, her family objects to her euthanasia. They enjoy visiting with C even though she fails to recognize them. It brings her family joy to see their mother happy at the seeming tedium of her everyday life. Moreover, they worry about the impact of the euthanasia procedure itself on their emotional wellbeing, and their memory of their mother. They accept the changes that dementia has wrought on their mother, and believe they could not live with themselves having euthanized C, even in her truncated state.

On a strong view of advance directives, C's family would be failing to respect their mother's precedent autonomy in seeking the nullification of a prior advance directive. In Dworkin's words, "Making someone die in a way that others approve, but he believes a horrifying contradiction of his life, is a devastating, odious form of tyranny."[51] But such an assertion misses a clearly relevant change which has occurred: namely, that C no longer has the capacity to think of her current state as a horrifying contradiction of her life. Moreover, those who would be affected by this supposed contradiction, who should, on Dworkin's view, be so offended at such a change, feel no such urge. On a minimalist account of advance directive, this fact alone is sufficient to nullify the advance directive. Insofar as the family of the patient have no current interests in preserving the advance directive, and in fact would be negatively affected by its execution, the obligations on healthcare professionals to abide by the directive are nonexistent.

[51] Dworkin, *Life's Dominion*, 217.

Since the only interests at hand in this case are the contemporary interests of the patient and their family, there is nothing objectionable, on my view, in the family forgoing C's past wishes. Further, the alternative to this conclusion would make little sense, and provide little benefit to those involved. The procedure of euthanasia may be confusing or distressing for the patient, who is now unaware of the values which made their younger self seek such a death. Euthanasia may be similarly distressing for the family, who have accepted their mother's current state, and see no reason for her to die immediately, even if they do not see her death as a prima facie harm at this stage in her Alzheimer's disease.

A second case presents an equally troubling occurrence, where a patient no longer remembers their advance directive, but other actors have strong interests in upholding their advance directive:

> **Case D**: D, an 87-year-old patient with late-stage Alzheimer's Dementia, crafted an advance euthanasia directive at the age of 80, specifying that she be euthanized at the point at which she can no longer recognize family, read, interact with other clients at her care home, and has global aphasia. She is worried, at the time, of becoming a "vegetable" without the capacity to live as she once did, a state which she believes in unbearable, and intolerable.
>
> In her current state, D meets these qualifications. Though D is in no obvious pain, eats sufficiently, and displays no emotional distress, she also shows no signs of pleasure or contentment. She does not react to stimuli, laugh, or smile. She has become the "vegetable" she once feared she would.
>
> Her family, keen to preserve her wishes, and distressed by the state their mother is now in, wish to carry out the euthanasia procedure. Despite this, D lacks the unbearable suffering on which her euthanasia directive was premised

In this case, my view conflicts with the weak view of advance directives. A weak view, on which a patient like D has changed sufficiently to warrant weakening or disregarding their advance directive, would endorse a best interests treatment standard. Such a standard would clearly not advocate euthanasia, since (among other reasons) there is no unbearable suffering which it would be in the patient's interest to relieve. But holding this standard is inconsistent with how we view death for such a patient. If, tomorrow, D was to contract pneumonia, we could rightly think that the best course of action would be for D to die – that we should work to prevent suffering, and provide a comfortable death. Death itself is not a harm to the patient in their current state, considering their lack of awareness and interest not only in their current affairs but also in any sort of future. At this point, our courses of action include either waiting for D to die naturally, or euthanizing her before such an illness takes hold. The former implies a more drawn out process which could involve suffering both for the patient and their family, all in the interest of lengthening D's life, which she has no interest in considering her state. The latter avoids such suffering, and does so without cost to any valuable life that D could have lived; it also confers a benefit of relieving (or avoiding) the suffering on behalf of family members. Even if we do not think that euthanasia is obligatory in this case, it is permissible, considering the lack of interest in continued life on behalf of D, and the interest in euthanasia on behalf of D's family.

We are unable to justify this latter course of action on a conventional account of advance directives which values precedent autonomy. But we can, and should, accept the administration of euthanasia in this case, as I argued above. But even if this

conclusion was accepted, a legal barrier remains in place which would preclude families from motivating for continued adherence to past critical interests. In the Netherlands, unbearable suffering must be confirmed before euthanasia is performed, regardless of if all other requirements are met at the time.[52] In Canada, unbearable suffering must be met in order to grant a request for assisted suicide or euthanasia (it remains to be seen if unbearable suffering must be confirmed at the time of euthanasia). The unbearable suffering standard for assisted death or euthanasia is a substantial barrier to patients' having their desires, and AEDs, fulfilled after they lose capacity.[53] We should abandon the unbearable suffering standard if we are to legalize advance euthanasia directives at all. Since the basis for euthanasia for dementia, with such a standard, is psychological suffering, which would not be present in late dementia (or the suffering present would not be reflective of the interests on which they based their directive), upholding such a standard would effectively mean that all euthanasia for dementia patients would be outlawed. This is despite the above case, where despite a lack of unbearable suffering, the euthanasia of the patient is permissible.

Cases **C** and **D** are important, since the strong and weak views of advance directives, respectively, fail to produce what I have argued are permissible outcomes. Further, these cases are not outlandish hypotheticals: we can each imagine ourselves in the position of these family members, caught between a desire to see our demented loved

[52] Regional Euthanasia Review Committees, "Annual Report 2017."
[53] Marike E. de Boer et al., "Advance Directives for Euthanasia in Dementia: Do Law-Based Opportunities Lead to More Euthanasia?," *Health Policy* 98, no. 2–3 (December 2010): 256–62, https://doi.org/10.1016/j.healthpol.2010.06.024.

one as their past self and a drive for the humane treatment of a bewildered, suffering patient. Some of us may have been put in this position already, albeit without euthanasia as an option. That a view which rejects precedent autonomy can produce permissible outcomes in each case is notable, and lends credence to my earlier suggestion that it is precedent autonomy which confounds our thinking about advance directives in the face of dementia. Yet it raises the question of the precise role that advance directives play on this experimental view of advance directives.

The explicit role of advance directives, in both of these cases, has been diminished. Indeed to say that advance directives, as they were articulated by the patient, have any guiding force in these decisions, would be incorrect. Nonetheless, they are likely to have some sort of implicit role in the decision-making process of the patient's family. The interests of the patient's family and friends, on a minimalist view, are what can justify the execution of an advance directive even after it lacks meaning for the patient themselves. Such interests would be informed by facts about the patient as they used to be: in seeking to treat their loved one as their pre-dementia self, they seek to treat them in a way that comports with their former values, when possible. Insofar as an advance directive accurately captures the past values of the patient, then, the loved ones of patients may rely on it to bolster their understanding of the patient's values. Advance directives, then, may serve a narrative role, providing a picture of the patient as they once were. But, on a view which rejects precedent autonomy, they do not in themselves generate obligations once a patient develops late stage dementia. It is the contemporary wishes of the family and friends affected by the treatment of the patient,

in balance with the experiential interests of the patient as they exist today, which must be taken into consideration.

§ 5.0 – CONCLUSION

This paper largely ignores the matter of justifying assisted suicide, euthanasia, or either of these actions in the face of a dementia diagnosis. This is not out of ignorance for the very active philosophical debate on the subject. Instead, I argue that granting the legalization of such a practice, a revision of our common conception of advance directives and euthanasia is necessary. Advance directives are far weaker than the orthodox view argues. We are not, as Dworkin argues, obligated to follow advance directives out of respect for precedent autonomy. They instead gain their power from the obligation to avoid a future situation in which a patient experiences a life in which their critical interests are thwarted. We follow advance directives because they help patients avoid situations they would experience as intolerable. We may allow the loved ones of dementia patients, however, to act as though the patient still shares in their past critical interests. This is permissible only where the desire of these loved ones does not impose a substantial experiential harm on the patient.

This paper does not prescribe euthanasia as the only course of action, nor does it prohibit the possibility that one may view dementia as not a corrupting force, but as a simple change. Perhaps, if such a viewpoint was embraced, patients at onset, and their families once the patients slip into late-stage dementia, would view the patient not as a

shell of their former self, but as a new version of the person they love, albeit with severely truncated abilities. We may view ourselves, if faced with a diagnosis of dementia, as someone who is soon going to experience a substantial change in perspective, but that this change was not necessarily harmful. Such a shift in conception would necessitate a change of perspective, on which this cognitive decline at the end of life is not met with grief, but of acceptance as a new stage of life. However unlikely I think this shift to be, and however difficult I find it to accept myself, such a shift in perspective on dementia would do nothing to complicate my view of how we should treat euthanasia directives if they are to be legal.

Dementia poses a significant challenge to our orthodox understanding of advance directives. Thus far, the argument has been framed as being about the threshold of similarity a demented patient has to their prior, competent selves. Those who hold strong views set the bar high, whereas those who hold weak views set it comparatively low. I sought to reframe this debate, exploring an account of advance directives which disregarded precedent autonomy. We can, as I have argued above, make sense of advance directives without the concept of precedent autonomy. Moreover, abandoning precedent autonomy results in permissible outcomes which would otherwise be impossible within one cogent understanding of advance directives.

The crippling blow that dementia deals to one’s autonomy and wellbeing, as well as the impact this disease has on families, should not be understated. But we should

recognize that the deprivation of autonomy by a disease cannot be remedied by precedent autonomy. We do not restore that which dementia has taken away by creating the façade that a patient still holds their past wishes. Though comforting, and at times permissible, the desire to treat patients as they once were cannot justify imposing harsh burdens on helpless patients who no longer understand the reasons behind their treatment. Instead, a balance must be struck between the interests of the current patient, and the interests of those who love and care for them.

BIBLIOGRAPHY

Albert, Marilyn S, Steven T DeKosky, Dennis Dickson, Bruno Dubois, Howard H Feldman, Nick C Fox, Anthony Gamst, et al. “The Diagnosis of Mild Cognitive Impairment Due to Alzheimer’s Disease: Recommendations from the National Institute on Aging-Alzheimer’s Association Workgroups on Diagnostic Guidelines for Alzheimer’s Disease.” *Alzheimer’s & Dementia* 7 (2011): 270–79. https://doi.org/10.1016/j.jalz.2011.03.008.

American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee. “American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement.” *Journal of the American Geriatrics Society* 62, no. 8 (August 2014): 1590–93. https://doi.org/10.1111/jgs.12924.

Arvanitakis, Zoe, Raj C. Shah, and David A. Bennett. “Diagnosis and Management of Dementia: Review.” *JAMA* 322, no. 16 (October 22, 2019): 1589. https://doi.org/10.1001/jama.2019.4782.

Boer, Marike E. de, Rose-Marie Dröes, Cees Jonker, Jan A. Eefsting, and Cees M.P.M. Hertogh. “Advance Directives for Euthanasia in Dementia: Do Law-Based Opportunities Lead to More Euthanasia?” *Health Policy* 98, no. 2–3 (December 2010): 256–62. https://doi.org/10.1016/j.healthpol.2010.06.024.

Bravo, Gina, Claudie Rodrigue, Marcel Arcand, Jocelyn Downie, Marie-France Dubois, Sharon Kaasalainen, C M P M Hertogh, Sophie Pautex, and Lieve Van den Block. “Nurses’ Perspectives on Whether Medical Aid in Dying Should Be Accessible to Incompetent Patients with Dementia: Findings from a Survey Conducted in Quebec, Canada.” *Geriatric Nursing* 39, no. 4 (July 2018): 393–99. https://doi.org/10.1016/j.gerinurse.2017.12.002.

Bravo, Gina, Claudie Rodrigue, Marcel Arcand, Jocelyn Downie, Marie-France Dubois, Sharon Kaasalainen, Cees M. Hertogh, Sophie Pautex, and Lieve Van den Block. “Are Informal Caregivers of Persons With Dementia Open to Extending Medical Aid in Dying to Incompetent Patients? Findings From a Survey Conducted in Quebec, Canada:” *Alzheimer Disease & Associated Disorders* 32, no. 3 (2018): 247–54. https://doi.org/10.1097/WAD.0000000000000238.

Bravo, Gina, Claudie Rodrigue, Marcel Arcand, Jocelyn Downie, Marie-France Dubois, Sharon Kaasalainen, Cees M. Hertogh, Sophie Pautex, Lieve Van den Block, and Lise Trottier. “Quebec Physicians’ Perspectives on Medical Aid in Dying for Incompetent Patients with Dementia.” *Canadian Journal of Public Health* 109, no. 5–6 (December 2018): 729–39. https://doi.org/10.17269/s41997-018-0115-9.

Cantor, Norman L. “On Avoiding Deep Dementia.” *Hastings Center Report* 48, no. 4 (2018): 26.

Clark, Suzannah, Tim Prescott, and Gemma Murphy. “The Lived Experiences of Dementia in Married Couple Relationships.” *Dementia* 18, no. 5 (July 2019): 1727–39. https://doi.org/10.1177/1471301217722034.

Davis, Dena S. “Alzheimer Disease and Pre-Emptive Suicide.” *Journal of Medical Ethics* 40, no. 8 (August 2014): 543–49. https://doi.org/10.1136/medethics-2012-101022.

Dresser, Rebecca. “Dworkin on Dementia: Elegant Theory, Questionable Policy.” Hastings Center Report 25, no. 6 (November 1995): 32. https://doi.org/10.2307/3527839.

———. “A Fate Worse Than Death?: How Biomarkers for Alzheimer’s Disease Could Affect End-of-Life Choices.” *Indiana Health Law Review* 12, no. 2 (October 27, 2015): 651. https://doi.org/10.18060/3911.0004.

———. “Treatment Decisions and Changing Selves.” *Journal of Medical Ethics* 41, no. 12 (December 2015): 975–76. https://doi.org/10.1136/medethics-2014-102237.

Dresser, Rebecca, and John Robertson. “Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach.” *Law, Medicine, and Health Care* 17, no. 3 (September 1989): 234–44. https://doi.org/10.1111/j.1748-720X.1989.tb01101.x.

Dworkin, Ronald. *Life’s Dominion*. New York: Vintage, 1992.

Health Canada. *Fourth Interim Report on Medical Assistance in Dying in Canada.*, 2019. http://publications.gc.ca/collections/collection_2019/sc-hc/H14-230-4-2019-eng.pdf.

Jaworska, Agnieszka. “Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value.” *Philosophy & Public Affairs* 28, no. 2 (April 1999): 105–38. https://doi.org/10.1111/j.1088-4963.1999.00105.x.

Kannaley, Kristie, Shreya Mehta, Brooks Yelton, and Daniela B Friedman. “Thematic Analysis of Blog Narratives Written by People with Alzheimer’s Disease and Other Dementias and Care Partners.” *Dementia* 18, no. 7–8 (November 2019): 3071–90. https://doi.org/10.1177/1471301218768162.

McMahan, Jeff. *The Ethics of Killing: Problems at the Margins of Life*. Oxford: Oxford University Press, 2002.

Parfit, Derek. *Reasons and Persons*. Oxford: Oxford University Press, 1984.

Regional Euthanasia Review Committees. “Annual Report 2017.” The Hague, Netherlands: Government of the Netherlands, April 2018.

https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports.

Rowe, Joel. “The Pandemic Should Change the Way We Talk About Dying.” *The Atlantic*, July 3, 2020. https://www.theatlantic.com/ideas/archive/2020/07/pandemic-should-change-way-we-talk-about-dying/613618/.

Walsh, Emily. “Cognitive Transformation, Dementia, and the Moral Weight of Advance Directives.” *American Journal of Bioethics* Forthcoming (2020).

VITA

Isaac Wright received his HBA (with distinction) in bioethics from the University of Toronto, Canada, in 2019. Immediately after the completion of the MBE from the Johns Hopkins Bloomberg School of Public Health, he will be pursuing a JD at University of Western Ontario Faculty of Law, Canada.